

# A Study on Stress among the Institutionalized Care Takers of Autistic Children

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## ABSTRACT

A day caring for a child with autism spectrum disorder can be challenging and stressful. Caregivers may take the child on various appointments, advocate for the child's educational needs, help the child avoid sensory overload, or deal with unexpected public tantrums. At the end of that long day, it may even be discouraging to learn that the child is unable to sleep and is preventing caregivers from getting the rest they need., face many unique challenges, but are not necessarily forced to lead stressful lives. Research shows that caregivers who use support systems to actively solve problems (including their own physical and mental health) are more likely than those who withdraw or coping in unhealthy ways have been shown to be much less stressful. It is a well-known fact that caregivers who are less stressed are more likely to raise children who are well-balanced and less anxious. The sampling method chosen was probabilistic sampling. In this study, researchers collected data from respondents using a simple random sampling method (lottery method). Research Universe: Current Research Universe is a contact from the Coimbatore District Autism Spectrum Disorder Center. Sampling: A sample size of 30 was collected based on the interview plan.

**KEYWORDS:** Care Takers and Autism Children

## INTRODUCTION

Caring for a child with an autism spectrum disorder is difficult and disrupts the caregiver's life. Emotional distress, depression, anxiety, and other mental or physical health issues are the most common symptoms caregivers face when caring for children with autism spectrum disorders. A growing body of research shows that mindfulness programs can help reduce stress for parents of children with autism. Programs generally consist of meditations that focus on body sensations and let go of thoughts. Some also include instructions for stressors and light stretching. You may find it difficult to manage your child's behavior, pay for medical care, keep a job, do household chores, or care for your child with autism. Parents and caregivers may be overwhelmed by this challenge, but over time they will most likely learn to cope and adapt to the situation.

## DEFINITION

According to **Hans Selye**, (1936), he stated that **stress** is 'the non-specific response of the body to any demand for change.

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The **WHO** defines **caretaker** as “a person who provides support and assistance, formal or informal, with various activities to person with disability or long-term conditions, or persons who are elderly”.

**Autism spectrum disorder (ASD)** is a pervasive neurodevelopment disorder characterized by impairments in social communication and restricted, repetitive patterns of behavior, interests or activities (**American Psychiatric association [APA], 2013**).

## Types of Caregiver Stress

Caregivers of children with autism face stress that can affect their mental, physical, social, and financial wellbeing.

**Psychological Stress:** Meeting the needs of a child with autism can increase a parents' risk of depression, anxiety, or other kinds of psychological distress. Parents who do not take steps to learn healthy coping strategies and disengage from caring for their mental health are likely to suffer even more stress.

**Physical Stress:** Chronic stress can make parents of children with autism more vulnerable to cardiovascular, immune system, and gastrointestinal issues. One study found that they are more likely to have higher levels of the stress hormone cortisol and a biomarker known as CRP, which has been linked to a variety of physical illnesses. Caregivers may also suffer from increased fatigue or struggle with insomnia, especially if their child also struggles with sleep.

**Social Stress:** Much of the general public is uneducated about autism spectrum disorder, and people may blame or shame a parent when they misunderstand a child's behaviors. This can create a stigma that can lead to parents feeling socially isolated. They might begin to avoid public gatherings or spending time with friends and family. Parents of children with autism may also be more likely to experience marital stress.

**Financial Stress:** Some research has found that parents of children with autism may earn less money or have to work fewer hours than other parents. Caregivers may also face additional expenses such as therapy, medical expenses, and child care that put an additional financial burden on the family. Some parents are even at risk of losing their jobs if they have to frequently take off work to care for their child.

## Review of Literature

### Neuropsychiatric Disease and Treatment (2016)

Previous studies carried out in Euro-American populations have unequivocally indicated that psychological disorders of the CASD (caregivers of children with autism spectrum disorder) are marked with high levels of stress, anxiety, and depression. This finding has been attributed to the reaction of having to care for a child with neurodevelopmental disorders. Therefore, there are strong grounds to contemplate the mechanism to help such a vulnerable group of family caregivers.

**Wei Wei Lai, Tian Po Oei, (2014)** Parents and caregivers of children with ASD have reported significant stress and challenges in caregiving. However, stress coping research in parents and caregivers of children remains limited. This review attempted to close this gap. For this review, 37 studies investigating the (1) underlying themes, (2) contributing factors, and (3) psychological outcomes of ASD-related parental and caregiver coping, were selected from the literature. This review emphasized the importance of further examination on the coping mechanisms of parents/caregivers of children with ASD.

**Ahmad Rayan, Muayyad Ahmad (2016)** Parents of children with autism spectrum disorder (ASD) frequently report poor psychological well-being. Previous research has supported mindfulness-based interventions to enhance psychological well-being in parents of children with ASD, but studies about this topic are still rare. The purpose of this study was to examine the effectiveness of brief mindfulness-based intervention (MBI) on perceived stress, anxiety, and depression among parents of children with ASD in Jordan.

## Methodology of the Study

### Objectives of the Study

- To find out the personal details of the respondents.
- To assess the levels of stress among institutionalized caretakers of autistic children.
- To investigate the influence of personal factors and coping mechanism of the respondents.
- To analyzed valuable suggestion about institutionalized caretakers of autistic children.

**Research design:** The researcher followed descriptive research design for the study.

**Universe of the study:** The aggregate of all the units pertaining to the study is called the population or the universe. Researcher selected the Autism Spectrum Disorder center Coimbatore District as the universe of the study.

**Sampling:** The sampling method adopted for the present study is probability sampling. For the present study the researcher use **simple random sampling** and lottery method to collect data from school students. In this manner using simple random sampling 30 respondents from Autism Spectrum Disorder Coimbatore District was selected as the sample for the present study total Autism students 42.

### Tools for data collection:

The Researcher Used Questionnaire as Tool of Data Collection. A five-point Likert scale was utilized to measure each indicator of latent variables ranging from (Excellent = 5; Very good = 4.5; Good = 3.7; Fair = 2; Poor = 1). Tool of data collection is self-prepared questionnaire and perceived stress scale.

The data were analyzed using various statistical tools like simple percentage, independent t-test, and ANOVA.

**Findings of the Study**

Factors	MEDIUM	FREQUENCY	PERCENT
Age	31-40	22	73%
Gender	Female	18	60%
Education qualification	10 <sup>th</sup>	21	70%
Family income	10000-45000	17	57%
Type of family	Nuclear family	19	63%
Father occupation	Coolie work	20	67%
No of dependents	2-3	27	90%

**Simple Percentage Analysis**

- Majority (73%) of the respondents is in the age group between 31-40 years.
- More than half (66%) of the respondents are female.
- Majority (70%) of the respondents are 10<sup>th</sup>.
- Nearly (57%) of the respondents family income level are 10000 -45000.
- More than half (63%) of the respondents are nuclear family.
- More than half (67%) of the respondents are coolie work.
- Majority (90%) of the respondents No of dependents are 2-3.

**DISTRIBUTION OF THE RESPONDENTS BY LEVEL OF STRESS**

S. No	Level of stress	No. of Respondents	Percentage%
1	High	35	58
2	Moderate	14	24
3	Low	11	18
<b>TOTAL</b>		<b>60</b>	<b>100</b>

**INTERPRETATION**

The above table demonstrates that (58%) of the respondents are having good level of stress, (24%) of the respondents are having moderate level of stress and the remaining (18%) of the respondents are having poor level of stress.

**INFLUENCE OF SOCIO ECONOMIC FACTORS AND LEVEL OF STRESS OF THE RESPONDENTS**

Variables	Statistical tool	Value	Result
Age and level of stress	ANOVA	F= .000 T<0.05	Significant
Gender and level of stress	t-test	t = 1.351 p>0.05	Not-Significant
Educational qualification and level of stress	ANOVA	F= .010 T<0.05	Significant
Family income and level of stress	ANOVA	F= .955 P>0.05	Not-Significant
Type of family and level of stress	t-test	t = .030 p<0.05	Significant
Father occupation and level of stress	ANOVA	F= .001 T<0.05	Significant
No of dependents and level of stress	ANOVA	F= .843 P>0.05	Not-Significant

- There is significant difference in the age and level of stress of the respondents.
- There is no significant difference in the gender and level of stress of the respondents.
- There is significant difference in the educational qualification and level of stress of the respondents.
- There is no significant difference in the family income and level of stress of the respondents.
- There is significant difference in the type of family and level of stress of the respondents.
- There is significant difference in the father occupation and level of stress of the respondents.
- There is no significant difference in the No of dependents and level of stress of the respondents.

## Recommendations

- A social worker should specialises in autism is often employed by a government agency, disability agency or self-help group to provide assistance and support to parents, children and adults with autism.
- Social workers should train in complex problem solving, as well as counselling, monitoring wellbeing and family support.
- Social workers who support individuals on the autism spectrum and their families engage in research, practice, education, and advocacy aimed at supporting individuals on the spectrum and their families, and to help communities enhance their awareness.
- Social workers should care for the children suffering with autistic spectrum disorder is challenging and affects the life of the caregivers.
- Social workers should motivated parents, teachers, and other caregivers can help children express their emotions through conversation, writing, drawing, playing, and singing.
- Spending time with other institutionalized caretakers who have similar interests, challenges, and experiences can reduce stress and feelings of isolation.
- It is helpful for institutionalized caretakers to set consistent routines as part of daily life. It will help to reduce stress.

## CONCLUSION

This study explored that autism is a spectrum disorder, now more commonly referred to as Autism Spectrum Disorder (ASD). This means that there are varying degrees of severity of autism. Some people with ASD are very verbal and talkative, while others do not use verbal communication. Similarly, some people with ASD become very withdrawn from all forms of social interaction, while others have families and jobs. This study depicts the stress of institutional caregivers of children with autism. Autism is a serious developmental disorder that affects the ability to communicate and interact. Autism spectrum disorders affect the nervous system and affect the general cognitive, emotional, social and physical health of those affected. We all know that caring for a child with autism is much more difficult than caring for a normal child. Stress levels were investigated and assessed. Finally, researchers were able to determine that institutional care for children with autism with high levels of stress does not exist.

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